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ABSTRACT

This extensive bibliography of books and articles provides an interdisciplinary overview of present day terminal care and the hospice alternative. Designed to aid in the development and implementation of terminal care programs stressing palliative and supportive services for both patients and their families, the bibliography includes abstracts of key titles and a subject index keyed to the entry numbers of the listed sources. (FM)

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THE HOSPICE: AN INTEGRATED BIBLIOGRAPHY

George E. Bodine, Ph.D. and William Sobotor
Department of Child and Family Studies
College for Human Development
Syracuse University

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PREFACE

The interest in the development of hospice programs in the United States has been nothing short of phenomenal. Within the past year, it has been estimated that over seventy-five hospice programs have begun across the United States, and in a number of other communities, plans are being developed which will lead to the implementation of additional programs.

As with any bibliography, this one suffers from the fact that it was out-of-date the moment it was written. The authors have plans to update this bibliography on a regular basis. They also plan to include, in the future, intervention programs which have been developed to assist the terminally ill and their families, and those which have provided support and counseling to the bereaved.

With a deep note of thanks we would like to cite the help and assistance of Stephanie Ardito-Kirkland, Project Director of the Gerontological Information Program, and Diane Sobotor. We would also like to thank Alethea - Center on Death and Dying of Syracuse and Dr. Pedro de Alarcon for providing both information and support.

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BACKGROUND

A direct outgrowth of increased interest in death and dying has been concern about the quality of one's dying and the nature of life just prior to death. C. Murray Parkes has written that, although medical science has enjoyed great success in its attempts to cure disease, we are, nevertheless, "faced with the unalterable conclusion that, no matter how hard we try, 100% of people still die". While proponents of scientific medicine find it very difficult to accept this fact, and are determined to postpone death at nearly any cost, others are appalled by the consequences which result from such a blind pursuit of the prolongation of life.

As a result of our advanced technology, modern medicine has evolved into a hard science at the expense of the patient and physician. Phillip Aries believes technology is a main factor in the trend toward depersonalization of death. Consequently, the patient has no control over this very personal stage of life, and the physician is enslaved by the technocracy that has pervaded his profession.

In an attempt to counter these trends and to return to a more "holistic" form of medicine, the Hospice concept has been revitalized. Growing from an initial effort at St. Joseph's Hospice in England, the idea has seized the attention of caregivers in many areas. Under the expert direction of Cicely Saunders, St. Christopher's Hospice in London has become the best known and has served as the prototype of many similar terminal care programs in Western nations. Presently, there are about 25 hospices in England and over 50 in various stages

of development in the United States.

All Hospices share basic, essential characteristics. The United States Congress has provided a federal definition of a Hospice:

> "...a program which provides palliative and supportive care for terminally ill patients and their families either directly or on a consulting basis with the patient's physician or another community agency such as the Visiting Nurse Association."[1]

Such an organized program of care places emphasis on the treatment of the patient as a member of the larger family system. The patient and family together are viewed as the unit of treatment. Such care includes pain relief, emotional support, spiritual support, and bereavement follow-up after the death has occurred. This care is delivered by an interdisciplinary team available on a 24 hour basis. While home care programs form the larger portion of Hospice services, in-patient facilities are usually available when the condition of the patient warrants hospitalization. Should hospitalization become necessary, the family is encouraged to continue in their own pattern of care provision. Clearly, the patient and family are never isolated from each other and maintain much the same relationships as in the pre-terminal phase of the illness.

This bibliography has been compiled from several sources and provides an interdisciplinary view of terminal care. Despite its scope, the references listed are readily available to anyone with access to a medical and college library. The interested reader will

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[1] United States Congress, House of Representatives. Committee on Interstate and Foreign Commerce, Subcommittee on Health and the Environment, A Discursive dictionary on health care. 94th Congress, 2nd Session, February 1976.

find little difficulty in locating any of the articles included. We have attempted to include a wide range of publications in order to provide an overall view of present day terminal care and the Hospice alternative.

Because the bibliography is so extensive, the authors have indicated key titles with an asterisk (*). These are abstracted beginning on page 20.

The following abbreviations have been used in the bibliography:

BMJ: British Medical Journal
CMAJ: Canadian Medical Association Journal
JAMA: Journal of the American Medical Association
NEJM: New England Journal of Medicine

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KEY TITLES (*) - ABSTRACTS

(Abstracts for numbers [illegible] are available in publications. However, they are considered to represent the information in those listed here.)

4. Anderson, W. Ferguson. A Death in the family--a professional view. British Medical Journal, January 6, 1973, pages 31-32.

Expresses need for public reassurance that people are not being kept alive by unusual measures in hospitals. The British Medical Association panel on euthanasia found that this idea is exaggerated. Confirms the belief that dying at home is most beneficial compared to institutionalization. Notes three important considerations in providing personal care: careful and accurate diagnosis; relief from pain; and close doctor and patient relationship. The article also discusses the need for support for the bereaved.

*5. Baier, Kurt. The Ethics of Positive Euthanasia, Critical Care Medicine, volume 4, number 6, November/December 1976, pages 317-319.

Discusses the three most general ethical principles involved in the euthanasia controversy. These principles are: (1) that everyone has a right to live if he wants to; (2) that everyone has a duty to live whether he wants to or not; and (3) that everyone has a right to die if he wants to.

*6. Barber, Bernard. Compassion in medicine--toward new definitions and new institutions, New England Journal of Medicine, volume 295, pages 959-963.

Compassion must be seen as an aspect of social systems and relations. These systems and relations are now changing, and so are the related roles of compassion. Four groups who could help ease the transition are cited: established medical professionals; young people just entering the profession; the government; and friendly but critical outsiders.

13. Bok, Sissela. Personal directions for care at the end of life, New England Journal of Medicine, volume 295, number 7, August 12, 1976, pages 367-369.

A growing number of persons are signing statements, often known as Living Wills, requesting that their lives not be unduly prolonged when there is no hope of recovery from illness. Although these documents carry considerable persuasive weight with medical personnel and relatives, they have not yet been recognized as legally

binding by the courts. Several states have legislation pending that would provide such legal recognition, and the courts may be prepared to give them weight even in the absence of legislation. It is likely that they will become increasingly influential as patient autonomy is strengthened, and as ways are sought to avoid the dehumanization and suffering that can accompany the ever growing ability to prolong life to a point that few would wish to reach.

16. Brantner, [illegible] "Life threatening disease as a manageable crisis", Seminars in Oncology, volume 1, number 2, June 1974, pages 133-137.

[illegible] psychological factors can be identified that make a significant [illegible] to the subsequent adjustment of people dealing with serious illness or other catastrophic situations: (1) [illegible] (2) depression (3) inactivity; and (4) isolation. The help in making a better adjustment and possible recovery intervention can be made in all four of these areas, even if it cannot [illegible] be made subtle and inobtrusive.

19. Buckingham, Robert. "Using the technique of participant observation", Canadian Medical Association Journal, volume 111, number 11, 1974, pages 1211-1213.

Through participant observation, questions concerning optimal care of dying patients and needs of their families were uncovered. A general surgical ward and a palliative care unit were the sites of observation. The observations support the belief that a palliative care unit, specifically designed to meet the known needs of dying patients and their families, is preferable to a general surgical ward. The main findings, of less concern in the palliative care unit than on the surgical ward, were the following: the importance of patient to patient support; the discomfort of sick role behaviour; the impersonal and sometimes intimidating nature of nursing care; the limitation of the patient's need (as a person) to give up control to others; and the value of families, student nurses and volunteers in [illegible] care. These findings emphasize the importance of personal interest to relieve the distress suffered by many terminally ill patients.

27. Catalano, Robert B. "The Medical approach to management of pain caused by cancer", Seminars in Oncology, volume 2, number 4, December 1975, pages 279-282.

Every physician at some time must manage pain associated with advanced cancer. In spite of the hopeless prognosis, the problem of pain deserves an intelligent appraisal and a systematic plan for relief to conserve the patient's physical, mental, and moral resources and social usefulness as long as possible. Selection of a method of tumor therapy from an array of alternatives depends solely on the

individual culture and careful consideration of the corporate structure, the responsibilities for success and the limitations, benefits, and risks.

34. Cooperman, Carl M. "Death Differentiate for the terminally ill and their families." Canadian Cultural Association Journal, volume XXX, March 5, 1973, pages 45-47.

[illegible] cultural evidence, and the study of the family case history [illegible] to use value in supporting conclusions for the plaintiff [illegible] and their children, both before and after death has occurred. [illegible] must be obtained not only at the culture but also at the [illegible] of this [illegible] and after.

[illegible]

[illegible] Journal of [illegible] volume 23, number 11, October 1972, pages 2-8.

[illegible]

[illegible]

[illegible]

in the American ethos of a positive definition for appropriate death that must be rectified in order to allow individuals to die meaningfully and with dignity.

43. Daniel, M.P. "The Social worker's role", British Medical Journal, January 6, 1973, pages 36-38.

Uses illustrative cases to point out the problems and needs of the dying person and the family. The patient is concerned with living while dying, or dying with dignity. The relatives carry on living by helping the dying of someone close to them. Both are in a process of "giving up, letting go, eventual separation and loss". The social worker has an ambiguous role in the process. Counseling is mainly social and personal but may also focus on day to day needs. The goal is to listen, to open communication in the family, and to share the experience. To remove the patient from reality is to withhold an opportunity which is a basic right of human beings. People should be allowed to work at completing their lives as they choose.

45. De Fouw, Ruth. "Hospices for the dying", The Humanist, July/August 1974, pages 28-29.

Describes the author's, a social worker's, visit to St. Luke's Nursing Home in Sheffield, England. Conveys the sense that care of the patient and family is paramount. Portrays the doctors and patients as very real people with personalities with pain to treat and care to give. The magic of the hospice is conveyed in this brief description.

53. Dunphy, J.E. "On caring for the patient with cancer", New England Journal of Medicine, volume 295, number 6, August 5, 1976, pages 313-319.

Death is as natural as birth. Regardless of religious belief, when the finality of death arrives, the patient acquires a singular equanimity. Under appropriate circumstances, the anxiety and fear of dying are reduced to a minimum. The role of the physician in accomplishing this goal is unbelievable, but instead of being duped by the illusion of euthanasia, the doctors must hail the spirit that permeates the Home of the Holy Ghost, St. Christopher's Hospice, and many other hospitals and institutions throughout the world. All we need to do is stand up and show the public that we understand.

61. Garner, J. "Palliative care--it's the quality of life remaining that matters", Canadian Medical Association Journal, volume 115, number 2, July 17, 1976, pages 129-130.

There are two things the health care system can do for a patient suffering a terminal illness. One is to relieve him of his pain, the other is to provide the most supportive possible kind of care. The

latter aspect is discussed in this article, especially focusing on the services provided at St. Christopher's Hospice in London and at the palliative care unit at Montreal's Royal Victoria Hospital. Palliative care entails a high staff to patient ratio and above all a different kind of nursing. The question as to whether a palliative care unit within a general hospital is less expensive than a separate hospice is being discussed. At the Royal Victoria Hospital, extensive use is being made of volunteers. The average length of stay and the role of religion are briefly described.

63. Gibson, Ronald. "Supporting the patient in the home", British Medical Journal, January 6, 1973, pages 35-36.

Describes the lack of understanding of death, particularly among medical students. Treatment and care of the dying requires much time which the hospital doctor does not seem to have. Home care is emphasized, noting the importance of an initial diagnosis and assessment in the hospital. The family, the general practitioner, and other home helpers must work together in providing care for the patient. Finally, the option of giving up home care should be available if the strain is too much for the family. The need for community support is expressed. The success of the hospice program is largely based on government commitment to community health care systems.

64. Gilmore, Anne J. "The Care and management of the dying patient in general practice", Practitioner, volume 213, number 1278, December 1974, pages 833-842.

A survey of a 10% random sample of Glasgow general practitioners has been made in order to examine how dying patients are managed in the community. The inherent problems of care that such patients pose to their general practitioners with regard to their medical and psychosocial needs are discussed.

72. Hackett, Thomas. "Psychological assistance for the dying patient and his family", Annual Review of Medicine, volume 27, 1976, pages 371-378.

Doctors, since the advent of modern medicine, have been far more concerned with curing than in caring for the incurable. The author, a physician, advocates dealing truthfully and compassionately with terminal patients and their families, and cites studies showing that this approach causes the patient less anxiety than evasiveness on the part of the health care team.

75. Hancock, Sheila. "A Death in the family--a lay view", British Medical Journal, January 6, 1973, pages 29-30.

Points out the problem with health professionals who view the terminally ill with insensitivity because technically this indicates a failure

on the part of the caregiver. A second problem for the lay person is a lack of information. There is a need for information on care available for the terminally ill as well as information on providing care in your own home. The author describes these difficulties in relation to dealing with her mother's death. Then, she describes the success she experienced in dealing with her husband's death with the help of St. Christopher's Hospice.

34. Holden Constance. "Hospices for the dying--relief from pain and fear", Science, volume 193, July 30, 1976, pages 389-391.

The article discusses the origins of the hospice movement with special reference to St. Christopher's Hospice in London. The use of analgesics, particularly the Brompton Mix, a cocktail of diamorphine (heroin), cocaine, gin, sugar syrup, and chlorpromzaine syrup, to eliminate pain in dying patients is described as an essential element in the care provided by hospices. Some of the unique features of St. Christopher's, which may explain its success, are described, such as the close knit community in which it is located. The potential of the hospice concept being integrated into the American health care system is examined with emphasis being placed on the efforts of the National Cancer Institute, which endorses the concept and funds experimental projects. Some American specialists in terminal care give their opinions as to the possible success or failure of hospices in the U.S. Finally, the relationship of hospices to euthanasia is examined.

33. Ingelfinger, F.J. "Empty slogan for the dying", New England Journal of Medicine, volume 291, volume 16, October 17, 1974, pages 845-846.

A discussion of the recent proliferation of literature on the subject of "death with dignity". The author contends that the procedures of hospitalization deny terminal patients any opportunity for privacy and dignity. As long as society demands the care that scientific medicine can offer, it is a deception to pretend that the process of dying can be invested with dignity: the most a doctor can do - and should do - is to mitigate the indignities that the patient must bear.

101. Kavanaugh, Robert E. "Humane treatment of the terminally ill", In Hoos, Rudolf H., editor. Coping with physical illness. New York: Plenum Medical Book Company, 1977, pages 413-419.

The author, a counseling psychologist, argues that a terminal patient should be told his prognosis as soon as it is medically certain. Citing the work of Kübler-Ross, which documented the emotional stages through which the dying pass, Kavanaugh contends that patients who know their destiny can progress toward a peaceful and dignified death. Those left in ignorance of their diagnosis rarely make it past the fearful stage of denial and isolation.

139. Liegner, Leonard M. "St. Christopher's Hospice, London--care of the dying patient", Journal of the American Medical Association, volume 234, December 8, 1975, pages 1047-1049.

After Dr. Cicely Saunders, director of St. Christopher's Hospice, had lectured at St. Luke's Hospital Center, a Hospice Committee was established to consider the introduction of similar concepts within the framework of a university general hospital. The author was invited to St. Christopher's for a visit in order to assist the committee in its deliberations. In this article, the author discusses his impressions of the hospice, placing particular emphasis on describing the physical environment, staff, typical admissions procedures, acclimation of the patient, drug therapy to alleviate pain and symptoms, psychiatric and religious counseling, population characteristics of the hospice, events surrounding the actual death of the patient, and the Bereavement Service, which maintains contact with the families of the deceased for various lengths of time to insure proper adjustment.

142. Markel, William and Virginia Simon. "The Hospice concept", CA--A Cancer Journal for Clinicians, volume 28, number 4, July/August 1978, pages 225-237.

The hospice concept of care for the terminally ill, long practiced in Europe, has recently been gaining acceptance in the United States. Changing attidues toward health care in general and toward the care of the dying in particular have created a milieu favorable to the development of programs based upon the hospice model. A hospice is an autonomous, centrally administered program of coordinated in- and outpatient services. This physician-directed program of health care delivery employs a multifaceted approach: narcotic and non-narcotic analgesics are used in physical sympton control, and the interdisciplinary hospice team provides psychologic, sociologic and spiritual services as they are needed. The patient and family is the primary unit of care and services are available on a 24-hour, seven-day-a-week basis. Hospice services are also available during the period of bereavement. Patients are usually accepted on the basis of health needs, rather than ability to pay.

145. McNulty, Barbara J. "Continuity of care", British Medical Journal, January 6, 1973, pages 38-39.

The author operated a liaison service between St. Christopher's Hospice and the surrounding community. This involved contacting patients who would eventually need terminal care and patients who moved back and forth from home to hospitals to the hospice. Service included advising health professionals on the management of terminal illness. Patients did not have to make unnecessary follow-up visits to the physician, yet, were not abandoned. Some recommendations are made to improve the success of home care. Many of the difficulties in providing terminal care stem from financial restrictions.

154. Mount B.M. "The Problem of caring for the dying in a general hospital--the palliative care unit as a possible solution", Canadian Medical Association Journal, volume 115, July 17, 1976, pages 119-121.

The general hospital as a setting for terminal care has disturbing deficiencies particularly, the medical, emotional, and spiritual needs of patients and their families are generally neglected. Consideration of the options for improving the situation led to the opening of the palliative care unit (PCU) at Royal Victoria Hospital, Montreal, which is staffed by an interdisciplinary team with a positive and creative attitude toward death and bereavement. The service comprises three areas of care - the PCU itself, a domiciliary service, and a consultative service - as well as research, teaching, and administrative functions.

172. Plant, J. "Funding a home for hospice care in the United States", Hospitals, volume 51, number 13, 1977, pages 53-62.

It can be hoped that hospice care will indeed influence mainstream medicine, which by tradition, seeks to cure and heal, at times aggressively. For those terminally ill patients who choose not to undergo countless, often painful, life extending measures, or for whom current curative medicine has been unable to relieve the racking pain, many believe an option should be available palliative therapy and medicine that picks up when curative medicine can do no more.

134. Rose, Mary Ann. "Problems families face in home care", American Journal of Nursing, March 1976, pages 416-418.

Report of a study of families of cancer patients, who had died between January and May 1973 and who had lived at home, sometime during the eight weeks preceding their deaths, were asked about the patient's physical care and the family's social functioning while the ill person was at home. Problems reported included: need for special equipment; need for education about home care; inadequate medical attention; problems transporting the patient to and from the hospital for treatment; interrupted and inadequate sleep for the caretakers.

196. Saunders, Cicely M. "A Death in the family--a professional view", British Medical Journal, January 6, 1973, pages 30-31.

The forerunner in the field of pain relief for the dying discusses pain control. Pain isolates, removing the patient from the family until it is controlled. Controlling pain need not require large doses of drugs if given regularly and if the physician pays careful attention to the patient's condition and complaints. The patient is not himself, and the family reacts to that, often in a negative manner. The patient and family need openness and a kind listener; hence, the author describes the need to "watch with me", rather than providing answers to the patient's fears.

204. Schoenberg, Bernard, et al., editors. Psychosocial aspects of terminal care. New York: Columbia University Press, 1972.

This book stems from the proceedings of an interdisciplinary symposium on the title subject. The symposium was intended to stimulate curriculum improvement in schools of the health professions so as to effect better care for the dying and their families. Workshops were given on education, on various aspects of medical care, psychosocial care, care of the family, and institutional care, and on ethical issues. There is considerable overlap of content among the various papers. Opinions vary primarily on the issue of who is to decide on the type of care to be selected. The book can serve as a meaningful source for curriculum development.

225. Twycross, R.G. "The Use of narcotic analgesics in terminal illness", Journal of Medical Ethics, volume 1, number 1, 1975, pages 10-17.

A group of 500 patients was reviewed. To achieve and maintain pain relief, many of the patients received diamorphine (heroin) regularly every four hours. Almost all the patients received phenothiazine concurrently: other drugs were prescribed when indicated. It was concluded that: although most patients receive parenteral diamorphine during the last 12 to 24 hours, the majority can be maintained on oral medication until this time: there is no single optimal dose of diamorphine: psychological dependence does not occur: physical dependence may develop but does not prevent the downward adjustment of the dose of diamorphine when considered clinically feasible: tolerance is not a practical problem: the prescription of diamorphine does not, by itself, lead to impairment of mental faculties. Also discussed are: the psychobiological nature of pain: the rational use of analgesics: the need for further research: the importance of the doctor's attitude.

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